GLENWOOD AND WOODWARD RESOURCE CENTERS
ANNUAL REPORT OF BARRIERS TO INTEGRATION

Calendar Year 2016

Introduction

Purpose of this report:

The Department of Justice settlement with the state Resource Centers (RCs) in November 2004 includes an agreement that the major barriers to each individual's move to the most integrated setting will be identified. The information is to be collected, aggregated, and analyzed. Annually the information is to be used to produce a comprehensive assessment of barriers that is provided to the Mental Health and Disability Services Commission and other appropriate agencies. Per the settlement, "If this information indicates action that the State can take to overcome barriers, taking into account the statutory authority of the State, the resources available to the State and the needs of others with mental disabilities, a plan will be developed by the State and appropriate steps taken."

Subject of this report:

This report contains data about the identified barriers of all persons residing in the Resource Centers' Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/ID) programs as of December 31, 2016 and who have at least one barrier to moving from the campus to a community setting. The data, analysis, and actions are combined for the Glenwood Resource Center (GRC) and the Woodward Resource Center (WRC).

Number of Individuals Residing at Resource Center ICF/IDs
(December 31, 2016)

	Adults	Under Age 18
GRC	227	0
WRC	141	1
Total	368	1

Definition of barrier:

Barriers are defined as "what prevents an individual from living in the community." These barriers indicate there is a need to increase community service providers' capacity to effectively meet the needs described in the barriers and help to address concerns of the individual, guardian or legal representative regarding living successfully in an integrated community setting.

Barrier Data and Discussion

Major Barrier Prevalence

(A person may, and often does, experience more than one barrier category)

Barrier	Definition	Under Age 18 %	Age 18 and Over %
Interfering behavior makes it difficult to ensure safety for self and/or others	The person has significant interfering behavior that requires supports for a person's safety or the safety of others. Interfering behaviors most commonly included in this category are aggression toward housemates, co-workers or staff; self-injurious behaviors; unhealthy obsessions (Pica, water intoxication, etc.); leaving the home or work area without notifying staff when unsupervised time creates a risk of harm to self or others; sexual offending behavior or sexual assault, over-familiarity or sexual promiscuity that could lead to victimization; and fire-setting.	1/1 100%	225/368 61%
Under-developed social skills	The ability to practice what community members commonly consider appropriate social skills is significantly impaired and affects the person's housing, jobs, support staff, housemates, or community members. Examples include extreme screaming, repeated verbal threats that result in concerns about safety for others, multiple unfounded accusations against staff, repeatedly invading personal space, inappropriate touch, loud or rude behavior that disrupts housemates' sleep or ability to interact with others.	0/1 0%	35/368 <10%

Barrier	Definition	Under Age 18 %	Age 18 and Over %
Health and safety	The person has multiple, severe, and/or sensitive health concerns that contribute to very fragile health and complex health care needs. The person may be unable to verbally report symptoms or accurately identify and request assistance with symptoms that could indicate that their health is at risk. The person may require specialized medical treatment and/or monitoring that is not readily available in the area of choice or the level of care they would prefer (e.g.: assistance with monitoring and administering injections for diabetes, fast and frequent access to monitoring/adjustment of adaptive equipment) etc.	0/1 0%	59/368 16%
Individual, family or guardian reluctance	Individual, family, and guardian reluctance to moving from RC environment to community supports. Examples of concerns cited: community providers' insufficient ability to provide supports necessary for success, lack of a safety net when support needs become more intense, the individual has lived in the RC setting for many years and considers it to be their home, difficult adjustment to change, limited community ability to provide continuous medical and behavioral support and consistent of active treatment as provided at the RC.	0/1 0%	252/368 68%

Discussion

Category: Safety due to Interfering Behavior

This includes safety of the individual, as in areas of self-injury, leaving the home or work area without notifying staff if unsupervised time creates a risk of harm, behavior toward others that invites others to cause harm to the individual, or lack of understanding of situations that place the individual at risk. A second, but equally important concern is safety of others, such as situations involving aggression, sexual assault, or fire-setting. The cost and ability to hire and maintain staff and training to provide these supports at the frequency, consistency, or level of need for the individuals served in the RCs often can be a challenge, especially for community providers. To be included in this category, interfering behavior(s) have been determined to currently be at a level of frequency or intensity that the supports needed are greater than are commonly offered by community providers. The percentage of people experiencing this barrier has been steady at 60% in 2014, and 61% in 2015 and 2016.

Category: Underdeveloped Social Skills

This area has to do with a need for further social skill development. Disruptive behavior is at a level of intensity that people around the person are unwilling or unable to tolerate living, working or socializing with the individual and making it very difficult for the individual to find housing, work, and staff support. Housemates may not have the opportunity participate in activities because this person has to be removed from social events, the provider may have difficulty maintaining consistent staff due to burn out or repeated threats and accusations, staff may have difficulty supporting others in the setting because of the intensity of need of this person. The number of people experiencing this barrier decreased from 35% of adults in 2012 to 25% in 2013, 11 % in 2014, and 8% in 2015, increasing slightly to 9.6% in 2016. The significant decrease in 2014 may in part be due to more in depth discussion and determination of what truly are barriers for some individuals being supported in the community. It may also reflect individual progress in learning skills and an increase in community ability to provide support.

Category: Health

This category has to do with individuals with significant medical needs. Barriers tend to be grouped into two specific areas. Often these individuals are older and are medically fragile; they frequently experience communication difficulties and rely on staff who knows them well enough to understand non-verbal signals and recognize signs of discomfort or medical need. Health is fragile enough that without staff ability to quickly recognize early and subtle signs of illness, the persons' health would be compromised. The other area is the need for quick access to adjustment and repairs for adaptive equipment (lifts, wheelchairs, bath carts, etc.) and the supports provided by quick access to professionals available at the RCs (doctors, nurses, physical, occupational and speech therapists on grounds or on call) make it difficult for many guardians to consider a move to a setting where those resources may not be as readily available. The number of people experiencing this barrier was 30% of adults in 2011, 2012, and 2013 and decreased to 22% in 2014, 20% in 2015, and 16% in 2016. The decrease may in part be due to more accurately determining what things are actual barriers. Other factors include some individuals passing away and some individuals moving to hospice or a skilled health care setting.

Category: Family/Guardian Reluctance

For many of the older individuals living in the Resource Centers, families have indicated that this has been their home for many years, and have expressed concern that a move would cause significant stress and loss for the person. For others, the move to the RC occurred following multiple discharges from community providers' services. Family members often react emotionally when approached about transitions to community services; they talk about their fears that a move to a community setting may not last, that their loved one will experience a long-term hospitalization due to a lack of community services to meet their support needs or that family members will be required to provide a home and care without enough support available to them. Family members express concern that the health of their loved one will be in jeopardy without the health care services at the RC and the trained, long term staff who know the person well and can identify early signs of a health concern. The number of people experiencing this barrier increased from 61% of adults in 2012 to 68% in 2013. The percentage continues nearly steady at 69% in 2014 and 68% in 2015 and 2016.

Decreasing census without seeing an increase in reluctant guardian percentage does indicate some progress being made in reducing the number of reluctant guardians.

Additional Comments:
We did not include data on lack of jobs or day activity as a barrier area because it is often not identified formally until a specific transition is being pursued. It is still important to note that this is a large concern. Day activity is key to success for many people, whether employment related or in a structured activity or volunteer setting. Meaningful day activity may be important for self-esteem, social, earning, and structure of the day. Lack of meaningful activity often leads to difficulty with interfering behaviors. Another barrier we hear identified by community providers is increased difficulty finding staff to hire in order to support current programs or to expand services. A barrier voiced by some providers is concern about fining by Department of Inspections and Appeals if they support someone with elopement issues and an elopement occurs. An additional barrier we heard as managed care started is uncertainty on the part of some providers as to whether the managed care organizations will consistently reimburse them at high enough rates to be able to support individuals with higher needs.

County Preference by Age Range & Gender
While some individuals have specified counties, cities and even neighborhoods where they would prefer to live, the people served at RCs have often searched for support options in those areas without success prior to their move to the RC. Many have indicated that they would consider options near, rather than in, their chosen area, in order to move more quickly back to the community setting. See Appendix A for map of regions.

REGION	AGE RANGE	MALE	FEMALE	Total
Central Iowa	Under 18	1	0	1
	18 to 25	3	1	4
69	26 to 40	22	4	26
	41 to 65	23	7	30
	Over 65	4	4	8
East Central Iowa	Under 18	0	0	0
	18 to 25	6	0	6
23	26 to 40	6	1	7
	41 to 65	4	3	7
	Over 65	3	0	3
North Central Iowa	Under 18	0	0	0
	18 to 25	1	0	1
	26 to 40	4	2	6
17	41 to 65	5	3	8
	Over 65	1	1	2
Northwest Iowa	Under 18	0	0	0
	18 to 25	0	0	0
8	26 to 40	5	0	5
	41 to 65	2	0	2
	Over 65	0	1	1

REGION	AGE RANGE	MALE	FEMALE	Total
Northeast Iowa	Under 18	0	0	0
	18 to 25	2	1	3
23	26 to 40	9	0	9
	41 to 65	4	3	7
	Over 65	3	1	4
South Central Iowa	Under 18	0	0	0
	18 to 25	0	1	1
	26 to 40	2	0	2
4	41 to 65	1	0	1
	Over 65	0	0	0
Southeast Iowa	Under 18	0	0	0
	18 to 25	1	1	2
5	26 to 40	2	0	2
	41 to 65	1	0	1
	Over 65	0	0	0
Southwest Iowa	Under 18	0	0	0
	18 to 25	0	1	1
36	26 to 40	9	9	18
	41 to 65	14	2	16
	Over 65	1	0	1
West Central Iowa	Under 18	0	0	0
	18 to 25	1	0	1
3	26 to 40	1	0	1
	41 to 65	0	0	0
	Over 65	0	1	1
Out of State	Under 18	0	0	0
	18 to 25	0	0	0
2	26 to 40	1	0	1
	41 to 65	1	0	1
	Over 65	0	0	0
Whole State	Under 18	0	0	0
	18 to 25	1	0	1
7	26 to 40	1	0	1
	41 to 65	4	1	5
	Over 65	0	0	0
No Preference identified	Under 18	0	0	0
	18 to 25	7	6	13
	26 to 40	24	9	35
205	41 to 65	95	31	126
	Over 65	25	6	31

Actions this Reporting Period

Overall

- Expanded Medicaid managed care, IA Health Link, has been effective since April 1, 2016. The case managers from the Managed Care Organization (MCOs) cover most individuals living at the Resource Centers (RCs). The MCO Case managers assigned to individuals at the Resource Centers are included as Interdisciplinary Team (IDT) members. Case managers met individuals, were given each individual's Individual Support Plan which includes information about preferences related to moving out and barriers to that, and began participating in some meetings and routinely receiving information. For people with Money Follows the Person (MFP), MFP transition specialists and MCO case managers were provided each other's contact information to assist in working together. The case managers are a resource in the transitioning process.
- Resource Center Social workers met with the United Health Care case manager and subject matter experts in transportation, transition, and the HCBS waivers. Discussed barriers to people moving out, educating guardians on community options, transition plan process and template.
- Resource Center Social workers had an initial meeting with the Amerigroup case manager, discussion included transition planning, communication, roles.
- AmeriHealth Caritas case manager especially supported the IDT and community provider through a very difficult period of supporting a person who had moved out. Result was the provider was able to continue providing services to the person.
- Continued to welcome providers to meet with us to learn about the support needs of individuals living at the RCs.
- Providers continued to visit people on campus and individuals continued to visit providers.
- For people moving in, typically requested guardian permission and if approved, made a referral to MFP grant services at or prior to a person's admission to the RC for assignment of a Transition Specialist.
- MFP transition specialists provided us some information about provider openings.
- Encouraged new providers or expanding providers to develop services in areas identified by families as needed.
- WRC changed social worker work assignments to utilize part of one position to assist all in discharge planning.

Interfering Behavior and Underdeveloped Social Skills in the Resource Centers

- Provided therapy and counseling support services at the RCs within groups and individually. Some topics and interventions include social skills; Dialectical Behavior Therapy (DBT) including mindfulness, anger management, and interpersonal communication skills; human sexuality; sex offender; social boundaries; reality therapy, victim support; positive life skills; relationships; problem solving.

- Used the trauma screening tool to ensure that all mental health needs are being covered for the persons in residence.
- Provided DBT training for new staff at orientation and offered this training as needed to individual team members. Provided Mindfulness skills from Acceptance and Commitment Therapy (ACT) training at the annual staff Skills Fair.
- Expanded and improved skills and training in applied behavioral analysis, positive behavior supports, DBT, sex offender treatment, and acceptance and commitment therapy.
- Created and went online with training on the Hierarchy of Interventions to all staff.
- Expanded and improved skills in working with individuals with inappropriate sexual behavior through literature reviews.
- Continued learning and incorporating ACT into practice – groups, programming, and individual.
- Developed curriculum using the Good Lives Model of sex offender treatment
- A WRC staff served on the Iowa Board of Directors for the Association of Behavior Analysis and now serves on one of their committees.
- The FACT (Functional Analysis Clinical Team) provided consultations for individuals on campus.
- Offered consultation and training to providers regarding people who do not live at the RCs. This expands provider skills, which may increase their ability to eventually support individuals moving from the Resource Centers. For the time period November 2015 - October 2016, the I-TABS program (Iowa Technical Assistance and Behavior Support program) provided support to 174 stakeholders via on-site and/or phone peer reviews and consultations, responded to requests for information from numerous callers, and did 35 presentations reaching 1600 attendees. Training topics included Understanding Behavior, Autism – Intro/School/Health Setting, I-TABS: Overview of Services, Helping Relationship, Reducing Aggression, Applied Behavior Analysis – Intro, Autism Spectrum Disorder – Sexuality, Behavioral Approach to Treatment in Health Care, Clinical Behavior Analysis, Emotional Avoidance – Sexual Offending, ID – Sexual Offending, Mental Health Diagnoses, MNASTA – Overview, PASRR – Behaviorally-Based Treatment Plans, Positive Behavior Supports – Supervisors. Audiences for training included Residential and Vocational Service Providers, Skilled Nursing Facilitates, Mary Greeley Medical Center, John Stoddard Cancer/Blank, Cherokee/Independence MHIs, Grandwood School, 2016 Iowa School Nurse Conference, 2016 Iowa Mental Health Conference, IBTSA Pre-service Training. Some areas I-TABS is working on in 2016 is developing and disseminating supports which reflect contextual behavior sciences such as DBT and ACT (Acceptance and Commitment Therapy/Training), emphasizing skill acquisition programs, clinical behavior analysis/ACT, and adult autism spectrum disorder supports.

- I-TABS noted an increase in requests for non-ID population, older, degenerative, post-accident conditions; blindness; deafness; racial/ethnic diversity. A decrease in training requests from HCBS providers. Other changes include MCO referral/attendance, Host Homes, focus on ACT, interest in ASD from Healthcare, PASRR Beh-Based Tx Plans/FAs, collaboration with I-START and APPLE. I-START began out of Waterloo in 2015, addressing the needs of individuals with co-occurring intellectual disabilities and mental illness.
- Agencies, both residential and vocational, received training as part of individuals' transitioning to their services. Topics included such things as individual routines, communication techniques, behavioral support plans, anticipated adjustment behavior, DBT, and autism. Training involved agency staff spending time at the RCs shadowing RC staff, RC staff spending time at the agency prior to move, day of move, and some overnights following move. RC staff also accompanied individuals to their new jobs, and assisted vocational staff as they helped the person adjust to new tasks and environments. A variety of staff were involved in providing the training such as direct support staff, supervisors, treatment program managers, psychologists, psychology assistants, physical nutritional management specialists, vocational staff, and social workers. Follow-up training was provided as needed during the transition period.
- The Autism Resource Team provided training to all new WRC staff at orientation.
- Provided services to individuals on campus in the area of inappropriate sexual behavior through the APPLE team which included staff trained by the Iowa Board for the Treatment of Sex Abusers. The APPLE team provided consultation and training to community providers regarding people they are serving in the community at this time.

Family/Person Reluctance

- Continued sending the guardians/families information about MFP and a provider list from the person's area of choice with the invitation to the person's annual review.
- Involved RC staff beyond social workers in visits with providers and follow-up visits to increase staff's comfort level with moves which in turn may increase confidence of families and individuals living at the RCs that community services can be successful in supporting an individual.
- Encouraged and assisted people to identify a preferred area of the state to live in so we can provide more detailed information about services available in that area and encourage guardians to develop relationships with providers and coordinators of disability services in the regions and educate them on the support needs of the individuals.
- Invited families to visit providers with us.
- Shared stories about people who have successfully moved via individual discussions with guardians and newsletters.
- Interdisciplinary teams continued to talk with guardians reluctant to move to obtain more specific information about their concerns in order to address those.

- Worked with MFP in the statewide stakeholder's workgroup.
- Information regarding provider services and individuals seeking housemates was shared with RC social workers from the Polk County Health Services provider meetings.
- Social workers continued to familiarize themselves with services and supports available across the state through visits to providers and providers meeting with the social work department on campus. Information about services available are shared with families/guardians as providers are identified who may be able to meet the needs of each individual.
- Social workers continue to have more frank discussions with guardians on census reduction, house consolidation, and general characteristics of the individuals who typically move into the RCs.

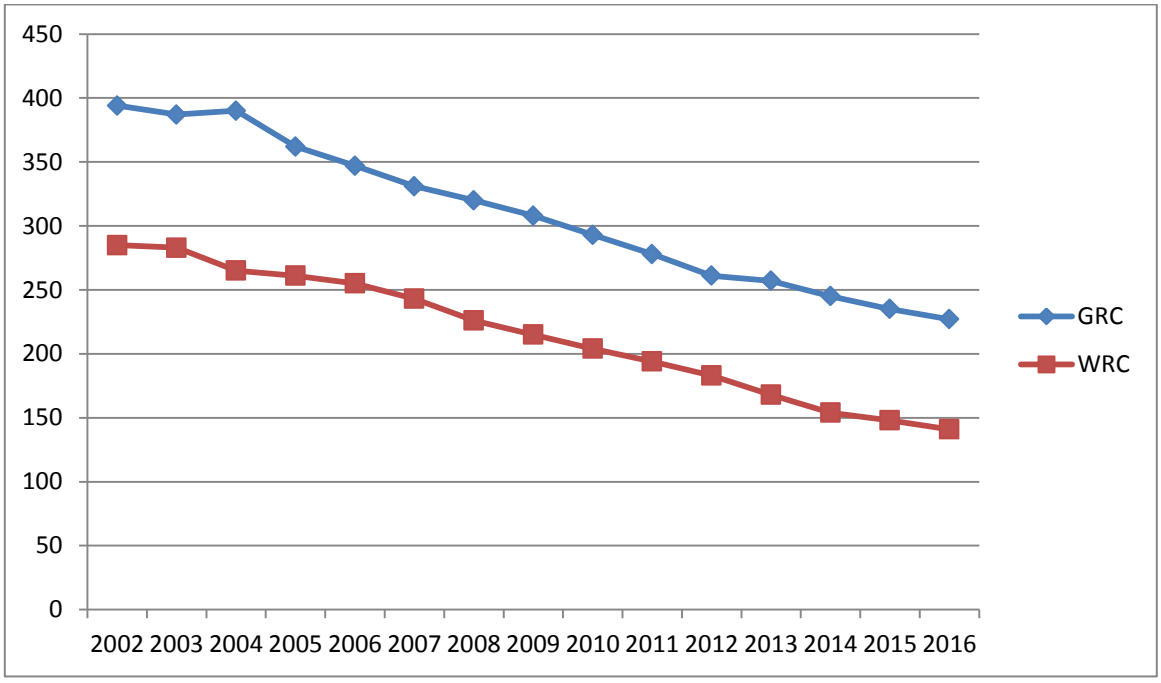
Health

- Increased our knowledge of community providers' ability to provide health supports
- Increased our awareness of providers who offer accessible housing and transportation via visits to providers, provider visits to campus.

Vocational

- Worked with the vocational specialist with the MFP grant.

Census Reduction



The census of the RCs has decreased as people have successfully moved to services with community providers. For a number of years, the RCs have had a specific census reduction goal and have accomplished this through helping people secure services with community providers and helping prevent the need for people to move in.

The RCs are committed to continuing to help people move to and stay in the communities of their choice. Some of the actions taken to accomplish this include:

- Educating others about the RCs' shift in role to shorter rather than long term residential services.
- An RC admission inquiry process that focuses on preventing the need for admission
- Treatment focus on the specific reasons the community providers are unable to support the person.
- Changing practices at the RCs to replicate what people experience living in the community.

The RCs place an emphasis on ensuring that people are moving with the appropriate services and supports to meet their needs and the moves can therefore be successful. The transition process includes:

- Comprehensive functional assessment to ensure essential supports for health and safety are identified

- A written transition plan developed by the IDT including the person, family/guardian, community provider(s), and case manager and includes a crisis plan.
- An individualized physical transition process that includes the person having visits from the provider staff and making visits to their new home before the move.
- Training of provider staff by the RC staff.
- Follow-up by the RC staff after the move.
- Inclusion of the case manager throughout the planning and move process and transfer of oversight to the case manager for follow-up after discharge from the RC

APPENDIX A

AREA OF CHOICE-MAP OF REGIONS